Diane E Meier, MD
Professor, Department of Geriatrics and Palliative Medicine
Mount Sinai School of Medicine
New York, NY 10029
diane.meier@mssm.edu
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Testimony against SB01076 AID IN DYING FOR TERMINALLY ILL

My name is Diane Meier, I am a physician and I specialize in geriatrics and palliative medicine. I have cared for thousands of people living with serious illness and their families. In this testimony I will argue that public policy legalizing access to physician aid in dying is unwise. Three considerations lead me to this conclusion. 1. The safeguards purported to prevent misuse are unrealistic and demonstrably ineffective; 2. Physicians are poor gatekeepers- we are imperfect and vulnerable humans, subject to internal and external pressures and, based on both past and recent evidence, not able to protect the most vulnerable from decisions made by others about the worthiness or unworthiness of their lives; and 3. Public policy must be based not only on

majority opinion but also on assuring protection from harms, especially for the most vulnerable.

1. Safeguards purported to prevent misuse are unrealistic and demonstrably ineffective

Prognostication: Physician prognostic assessments are notoriously wrong, and the great majority of deaths (78%) are due to chronic illnesses where death cannot be reliably predicted (heart and lung disease, dementia, and many chronic cancer conditions). In other countries, including Canada, Belgium, and the Netherlands, a poor (<6 month) prognosis is not requiredrather the patient and physicians' assessment of the degree of "irremediable suffering" is the key variable. This implies that suffering per se is sufficient justification, that elimination of suffering is a valid expectation and societal goal, a conclusion that opens the door to aid in dying for anyone who says they are suffering.

Determination of patient's decisional capacity (aka a "sound mind") is not simple and requires training- (which most physicians have never had) and sufficient time (which no physician has) to assess the patient's ability to articulate their understanding of their medical circumstances, their fears about what the future holds, their treatment options and the pros and cons of each, and the ability to communicate a decision based on a clear and consistent rationale. What sounds like a rational decision is often a cover for depression, hopelessness, rage, and fear, all of which are complex, hard to talk about, and time intensive. Shortcuts are inevitable given the lack of training and lack of time characterizing most physicians' day-to-day practices.

Identification and treatment of depression: Physicians miss the diagnosis of depression in the majority of patients and many are unaware that depression is a treatable and remediable disorder

Despite the regulatory requirement that doctors refer for psychiatric consultation if they suspect depression, such referral rarely takes place, whether because depression is unrecognized or because it is a hassle to make the referral and the patient will be angry about it, or the doctor feels it is appropriate to the circumstances, is unknown. In Holland and Belgium and soon, Canada, psychological suffering is eligible for medical aid in dying. Existential distress about real or anticipated losses is a universal condition of human life and not an adequate basis for expecting physicians to help to end that life. Fixing all suffering is not given to us.

Perhaps because the criteria are unrealistic, there is evidence of what I will call eligibility creep. Others might call it a slippery slope. As communities of doctors become more accustomed to helping people to die, it becomes easier and easier to enable a broader group of sufferers the same privilege. Recent literature

and media coverage from Holland and Belgium and now Canada on physician's growing willingness to help non-terminal patients including the demented, disabled, mentally ill, and children to die, suggest the real possibility of the slippery slope, provision of medical aid in dying "based on the judgment by others that these lives are not worth living." This evidence suggests that regulatory safeguards are ineffective at protecting patients and society from misapplication of medical aid in dying to ineligible patients.

The reality of family coercion: Pressure from families and overwhelmed healthcare systems is a reality. Physicians involved in medical aid in dying described feeling intimidated and coerced ("I learned very quickly that the patient's agenda was to get the medication. When I try to talk them out of it, or to really assess their motivations, then they perceived me as obstructionist and became quite resentful..." (Ganzini 2003) Others stated that they felt they had to accede to the request for fear of disappointing the family. (Stevens KR 2006) Family coercion is described in multiple publications, a force difficult to resist for both vulnerable patients already aware of the multidimensional burdens their

needs are imposing on their families-- and physicians. Given the enormous burdens of care imposed on families and other caregivers when a loved one is seriously ill, access to a legal option to avoid a long period of debility and need for costly personal care has undeniable appeal-but not necessarily to the patient. I have personally experienced this in NYS where medical aid in dying remains- for the moment- illegal. In one instance I was contacted by email by the wife of a patient with recurrent glioblastoma to discuss his care options. Because of his mobility difficulties, I visited them at home. It quickly became clear that the purpose of the visit was to see if I would help to hasten his death. When I began to explore what had precipitated this request and asked what the patient feared about the future, he looked at his wife and did not answer- his wife did. I explained the benefits of palliative care in terms of symptom relief and support for both patient and the family throughout the remainder of his life- the patient was interested and asked several questions about what home care options were available and about what the process of dying was actually like. I described it. He seemed reassured. His wife however, appeared more and more irritated saying "we know all about hospice and we are not interested." When I asked to speak with him individually, she thanked me for coming and

escorted me to the door. Had aid in dying been legal in NY at the time I have no doubt that she would have found a willing prescriber and helped her husband – who had months to years to live- to hasten his death. When family members are stressed and burdened by the role, when the illness is bankrupting the family, the patient gets the message.

The facility with which US and European doctors and scientists accepted the "rationality" of eliminating the infirm or ill through eugenics in the last century (to work toward a healthier society), and the notion intrinsic to eugenics that some lives are worthier than others should give us pause. Legalization of medical aid in dying explicitly endorses the acceptability that some lives are not worth living. We do not have to look too far back in history to recognize that this carries risk.

What should happen when a patient requests help to die?

Evaluation of a patient requesting help to die, should first and foremost, be a response to the patient's expression of despair, of their belief or fear that life in the future will be unbearable. In

support of the influence of fear on requests for aid in dying, the desire to die diminishes over time among the terminally ill, perhaps because of the benefit of support and treatment of depression, perhaps because of resilience in adjusting to a new normal (example of spinal cord injured patients) and perhaps because the reality turns out not to be as bad as the fantasy. (Chochinov HM 1995) In any suicidal patient, the request for medical aid in dying is also an expression of despair- an effort to communicate with their doctor the patient's fear that their continued life no longer has value and meaning to themselves or to others. Given the reality of family caregiver burden and coercion and declining societal capacity to provide the needed supports, the physician is the one person ethically and professionally obligated to stay on the side of the patient's continued life.

The Role of Public Policy The assumption that all physicians covered under a policy legalizing physician aid in dying (all licensed physicians) are equally capable of responding appropriately, carefully, and patiently to such requests would be funny if it were not so absurd and frightening. A public policy, by definition, has to protect the public from harm – in this instance such protection cannot be insured by safeguards--as the majority of physicians in practice have neither the training, time, or even interest to help their distressed patients find reasons to live, nor does society seem interested in paying for the resources that would be necessary to do so. Multiple examples, in both Canada and the US, confirm that poverty, housing insecurity, need for paid personal care aides, mental illness, and overwhelming family caregiver burden are often the primary motivator behind the request. Other patients did not request but have been offered aid in dying by clinicians as an alternative when needed support services were not available. Indeed, a Canadian

Study conservatively estimated \$140M in savings to the government with AS/E on the books. Multiple commentators have called out the rapid rise in deaths by aid in dying, accounting for about 3.5% of Canadian deaths last year, and rising. The claim that MAID would never serve as a substitute for access to palliative care and social supports is hollow- medical aid in dying is an inexpensive and fast drug treatment. Effective palliative and mental health treatments and social supports require real skill, time, and resources- that society has thus far not been willing to provide. These concerns are not hypothetical.

Multiple real examples of abuses- people receiving MAID who should not have- are available: Several are listed below:

- 1. Recordings of <u>Roger Foley</u>, a man with disabilities in Canada being pressured by hospital to die by assisted suicide. <u>He's suing</u>.
- 2. A <u>veteran</u> in Canada was offered euthanasia for PTSD by their VA.

- 3. Another Canadian <u>veteran and Paralympian</u> offered euthanasia by the Canadian VA when she requested a lift to independently get herself from her bed to her wheelchair.
- 4. A <u>young man</u> in Canada with clinical depression and partial blindness was approved for hastened death.
- 5. <u>Canadians in poverty</u> are requesting assisted suicide/euthanasia and are, in some cases, being approved
- A Canadian woman with disabilities could not afford <u>accessible housing</u> on her equivalent to SS Disability support from the government and is approved for euthanasia.
- 7. Story with several <u>disabled Canadians</u> cannot afford their Long Term Services and Supports, pain care, and/or food, opt for AS/E.
- 8. Canadian doctors pushing for euthanasia of <u>significantly</u> disabled infants.
- 9. Exposé of the Canadian MAID programme by an American journalist with <u>recordings of CAMAP doctors</u> acknowledging people are getting AS/E due to poverty and lack of services/access to care and how to get around their qualms. A synopsis of this fairly lengthy piece <u>HERE</u>.

It is challenging and emotionally exhausting to accompany patients through a difficult illness. When the patient asks and indeed may insist, when overwhelmed and burdened families put pressure on doctors, when the law permits, when your colleagues are doing it, and when the supports (such as personal care or

housing) are not covered, when daily efforts required to try to avoid it are exhausting, writing the prescription becomes- by farthe easiest – and cheapest- thing to do. While the harm it causes to patients themselves is obvious, state-sanctioning of hastened death as a solution to a difficult problem sends powerful and corrosive messages about the value of human life to everyone in society. Suicide rates in people over 65 have risen by 14% in concert with medical aid in dying legalization. What kind of society will we become? The most vulnerable-potentially any one of us who can no longer work- are offered a quick death, rather than the care and supports they need.

In closing, I can imagine that I might like to have the option of medical aid in dying at some point in my future. However, my personal preference does not outweigh the very real risks of public policy normalizing state-sanctioned suicide. Such a change

in policy puts tens of thousands of my fellow citizens, particularly the poor, the disabled, the chronically ill – the highest need and highest cost people among us – at risk of being coerced to die because our society will not pay for what people need in order to live. Public policy must protect the most vulnerable among us and their trust in their doctors and in their society. In one published description (Hamilton 1998) a man with advanced COPD asked his physician, "Can't you do something to just bring it to an end ?...Just put me out of my misery. It would save everyone a lot of trouble." The doctor replied, "... Even though you feel like a burden, I can't do that." The patient asks, "Why not? You'd do it for your dog." The doctor answers "Because you aren't a dog. You're my patient and I'm your doctor, and I'm trying to help you. And I'll keep trying to help you as long as I can." The patient took the doctor's hand in both of his and said, "Thank god, I thought everyone had given up on me." Confirming this case study, Barnard wrote in 1995 "The sting of illness and death is the

specter of broken relationships and the loss of the world. Over and against this threat stand the effort of caregivers and companions to embrace the sufferer and continuously reaffirm his or her capacity for relationship." (Barnard D. 1995)